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## Living with a partner with dementia

*a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives*

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*Published in:*  
Aging & Mental Health

*DOI (link to publication from Publisher):*  
[10.1080/13607863.2018.1433634](https://doi.org/10.1080/13607863.2018.1433634)

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*Publication date:*  
2019

*Document Version*  
Publisher's PDF, also known as Version of record

[Link to publication from Aalborg University](#)

*Citation for published version (APA):*

Egilstroed, B., Ravn, M. B., & Petersen, K. S. (2019). Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives. *Aging & Mental Health*, 23(5), 541-550. <https://doi.org/10.1080/13607863.2018.1433634>

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To cite this article: Barbara Egilstrod, Maiken Bay Ravn & Kirsten Schultz Petersen (2019) Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives, *Aging & Mental Health*, 23:5, 541-550, DOI: [10.1080/13607863.2018.1433634](https://doi.org/10.1080/13607863.2018.1433634)

To link to this article: <https://doi.org/10.1080/13607863.2018.1433634>



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Published online: 06 Feb 2018.



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# Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives

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## ABSTRACT

**Objectives:** Dementia causes dramatic changes in everyday-living for spouses. Occurred changes in marital relationship, force spouses to perform more both mentally and physically. Leading to a spousal perceived burden. To improve understanding of spouses' needs, spouses lived experiences is needed. The aim was to identify and synthesise qualitative studies on spouses' lived experiences of living with a partner with dementia.

**Methods:** A systematic search was undertaken in January 2017. Six databases (CINAHL, Cochrane Library, Embase, PubMed, PsycINFO and Sociological Abstracts) were searched, using search terms in accordance with PICO. A descriptive synthesis and a thematic synthesis were undertaken.

**Findings:** Fifteen studies met the inclusion criteria. Three themes derived from the analysis 1) Noticing changes in everyday life 2) Transformation to a new marital relation in everyday life, with corresponding sub-themes; changes in marital relationship, management of the transitioned marital relation in everyday life 3) Planning the future.

**Conclusion:** Findings provide an overview of how spouses notice changes and transform their marital relationships in everyday-life. Findings offer a deeper understanding of changes that occurs over time while the partner is living at home. Findings contribute with knowledge on spouses' experiences of changes in early-stages of dementia. Interventions supporting spouses are needed.

## ARTICLE HISTORY

Received 11 August 2017  
Accepted 22 January 2018

## KEYWORDS

Spouses; dementia and cognitive disorders; lived experiences; everyday life; review

## Introduction

Dementia is a common reason for needing time-intensive care, and spouses are among caregivers very likely to support their partners in activities of daily living (ADL) (National Alliance for Caregiving (NAC) AARP Public Policy Institute, 2015). Previous reviews have found an association between perceived caregiver burden and informal care due to the hours involved in care, stress, depression, anxiety, social isolation and lack of social resources (Allen et al., 2017; Chiao, Wu, & Hsiao, 2015; Ornstein & Gaugler, 2012; Sansoni, Anderson, Varona, & Varela, 2013). Assuming a role as caregivers, spouses often experience grief and multiple losses, including loss of partner and personal freedom (Chan, Livingston, Jones, & Sampson, 2013).

Western Europe has the highest prevalence of persons living with dementia, estimated at 7.0 million, and this number is expected to increase by 40% over the next 20 years (World health Organization, 2012). Due to challenges in managing the changes brought about by dementia, multiple strategies have been launched. Worldwide, a multisector approach that targets the needs and perspectives of persons with dementia and their relatives has been prioritised (Sundheds- og Ældreministeriet [The Ministry of Health], 2016; World health Organization, 2012). Interventions that are aimed at caregivers predominantly focus on education programmes, including the provision of coping and support strategies and self-management support (Dam, De Vugt, Klinkenberg, Verhey, & Van Boxtel, 2016; Gilhooly et al., 2016; Huis in het Veld,

Verkaik, Mistiaen, van Meijel, & Francke, 2015; Jensen, Agbata, Canavan, & McCarthy, 2015; Letts et al., 2011; Li, Cooper, Austin, & Livingston, 2013; Vandepitte et al., 2016).

Education programmes have shown a moderate reduction in caregiver burden and depression (Jensen, Agbata, Canavan, & McCarthy, 2015; Parker, Mills, & Abbey, 2008). Coping strategy interventions are efficacious in decreasing depression, but are followed by an increase in dysfunctional coping immediately after the interventions have ended (Li et al., 2013). A review of social support interventions showed no positive effects in quantitative studies; however, qualitative studies showed that spouses felt more emotionally supported and less socially isolated (Dam et al., 2016).

Most former reviews of qualitative studies focus on the lived experience from the perspective of various caregivers or from a couple's mutual perspective (Evans & Lee, 2014; Quinn, Clare, & Woods, 2009; Wadham, Simpson, Rust, & Murray, 2016). Changes in marital relationship are often followed by spouses' experience of loss, grief and a feeling of uncertainty in relation to the new living situation (Evans & Lee, 2014). Hence, some studies report positive outcomes of spouse caregiving (Pretorius, Walker, & Heyns, 2009; Shim, Barroso, Gilliss, & Davis, 2013). Studies of the lived experience from the perspective of spouses of people with dementia are sparse. Spouses seem to manage these changes by accepting and adapting to their new circumstances (Evans & Lee, 2014; Pozzebon, Douglas, & Ames, 2016). Studies on how marital life is managed in everyday life in the early stages of dementia could yield insight into the above-mentioned challenges.

However, to improve our understanding of the needs of spouses living with a person with dementia, a systematic review of previous studies is needed. Such a review could support the development of interventions targeting the early stages of dementia while living at home. The aim of this study is thus to identify and synthesise previous qualitative studies on what characterises spouses' lived experiences of living with a partner diagnosed with dementia, and how changes in their everyday lives are managed.

## Methods

This systematic review and thematic analysis of qualitative studies of spouses' lived experiences follows Joanna Briggs' Institute (JBI) review guidelines (Joanna Briggs Institute, 2014). Lay representatives with experiences of being spouses to a partner with dementia participated in The Review Panel (panel). The panel consisted of a voluntarily established spousal caregiver support group including five individuals with a partner with dementia or a partner who had lost a husband or wife due to dementia. The first author and the panel met twice on a joint meeting and discussed the aim of the study and the results in order to reflect on the lay perspective during the review process.

## Search strategy and criteria

A systematic search was conducted in six databases: CINAHL, Cochrane Library, Embase, PubMed, PsycINFO and Sociological Abstracts, from 24 January to 10 February 2017.

The PICO process as recommended by Joanna Briggs was used to formulate a focussed research question that contained research terms that related to **P** (population), **I** (phe-

nomena of interests) and **Co** (context) (Joanna Briggs Institute, 2014), and the systematic search in all six databases was structured around PICO, illustrated in Table 1. The systematic search was first conducted in PsycINFO and then adapted to the other databases. The phenomenon of interest was defined according to Birte Bech-Jørgensen's concepts of everyday life and used to formulate research questions and to choose relevant search terms (Bech-Jørgensen, 1994). According to Bech-Jørgensen, 1994, 'everyday life' can be defined as the circumstances under which a person is living, and the term 'management' used in the research question refers to how individuals are able to manage these circumstances (Bech-Jørgensen, 1994). Spouses living with a partner with dementia at home were chosen in order to capture the challenges experienced in the early stages of dementia.

Subject headings were adjusted in each database due to variations in the predefined subject heading in the thesaurus in the different databases. Truncation of search terms was used to capture word inflection, except in PubMed because of an automatic deactivation of underlying functions. A methodological filter was used in PsycINFO. In the remaining databases, manual methodological filters (Glanville et al., 2008; Saini & Shlonsky, 2012) were developed due to the unavailability of methodological limits in the databases (Table 2). Inclusion and exclusion criteria are presented in Table 3.

## Inclusion procedure

The inclusion process consisted of two screening steps. Firstly, all identified articles from the systematic search were screened by title and abstracts according to pre-defined criteria. Secondly, the identified studies were divided between authors (two thirds each), so that full-text articles were

**Table 1.** Example of the systematic search, built in PsycINFO, illustrating a facet search, including facets 1, 2 and 3.

Facet 1 P: Spouses	Facet 2 I: Everyday life	Facet 3 Co: Dementia
Caregivers or Spouses or Couples or 'Significant others' as subject headings and Caregiv* or Spous* or Husband* or Wif* or Wiv* or Coupl* or 'Spousal care*' as free text	'Daily activities', 'Life experiences', 'Life changes' as subject heading and 'Daily activitie*' or 'Everyday living*' or 'Living*' or 'Life experience*' or 'Life Chang*' as free text	'Dementia+' or 'Alzheimer's disease' as subject headings and Dement* or Alzheim* or "Senile dement*" as free text

**Table 2.** Methodological limits used in CINAHL, Cochrane, Embase, PubMed and Sociological Abstracts. Filters varied between the databases, illustrated in facet search as the fourth facet.

Facet 4 Methodological limits
Qualitative methods: 'Qualitative studies+' or 'Focus Groups' or 'Interviews+' or 'Narratives' or 'Life Histories' or 'Observational Methods+' or 'Biographies' as subject headings and 'qualitative stud*' or 'qualitative research*' or Biograph* or *Narrative* or 'Life History'

**Table 3.** Inclusion and exclusion criteria.

Inclusion and exclusion criteria	
Population	<i>Inclusion:</i> Family and couple/dyads' perspective, where focus is on a spousal perspective as a part of the study. Partners living together, which included cohabitants and spouses. <i>Exclusion:</i> Families' or children's perspective that did not cover a spousal perspective as a part of the study. Specific focus on a gay perspective was excluded.
Phenomena of interest	<i>Inclusion:</i> The lived experience of everyday life
Context	<i>Inclusion:</i> Living with a partner, at home, in early stages of dementia, i.e. mild-to-moderate degree of dementia. Studies where the degree of dementia was unclear were included. <i>Exclusion:</i> Partners living in institutional care and/or with severe dementia and/or multiple diseases, families with children living at home
Characteristics of studies	<i>Inclusion:</i> Qualitative studies, published in English, from January 2007 until May 2017 <i>Exclusion:</i> Intervention studies.

screened by at least two authors according to the criteria and quality assessed by the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Program, 2017). Criteria and quality assessment were discussed at a joint meeting, and any discrepancies were discussed until consensus was reached.

### Analysis

The analysis consisted of two steps. Firstly, a descriptive analysis was performed by the first author, aiming to index and summarise the included studies. Indexed studies are presented in a review matrix (Table 4) including author, year, country and journal, purpose, methods, analytical strategy and results, as headings (Garrard, 2007). Secondly, a thematic analysis, inspired by Thomas, Harden, Thomas, and Harden (2008), was conducted involving all authors in the discussion of the themes. Study results with particular focus on spouses' experiences of stages, changes and management with respect to the duration and the development of dementia formed the basis of the descriptive themes. Responses received from the panel confirmed the importance of looking deeper into how everyday life is experienced as dementia progresses, and this helped qualify the aim of the review and the following analysis.

Data were obtained by following the steps in the inductive thematic analysis (Thomas et al., 2008). The analysis had particular focus on coding what characterised the spouses' lived experience, and how the challenges experienced in everyday life were managed. The analysis was constructed as follows:

- (1) Line-by-line codes and related themes were extracted on the basis of the studies' findings with the research question in mind.
- (2) Freely lined codes and related themes were organised and then reorganised into broader descriptive themes, within and across the studies' findings. Firstly, articles focusing solely on changes and management were coded into two broader themes. Secondly, articles with both themes incorporated were coded and added to the two broader themes.
- (3) The descriptive themes formed the basis for the next level of the analysis where a synthesis was made across the studies' findings, leading to the final interpretation.

After several revisions and discussion of the analysis, a timeline was drawn up based on the thematic analysis, showing how everyday life was experienced and managed from the time of pre-diagnosis of dementia to the time where the marital relationship started to transform and to the time of consideration about the future.

### Quality assessment

As the literature search produced only a limited number of studies, it was decided to reject no studies due to low quality. The quality assessment of the individual studies is inspired by Joanna Briggs and presented as a narrative summary of the overall methodological quality of all the studies (Table 5). Q1 till Q10 represent the ten questions from the CASP checklist which we used to assess the quality of each study. Yes (Y) and No (N) address if and if not each of the studies lived up to the quality question.

## Findings

### Identification and classification of studies

The systematic search produced 2,430 hits, of which 570 were duplicates (Figure 1). 1,860 studies were screened first by title and abstract, resulting in exclusion of 1,645 studies which did not live up to the inclusion criteria. Full-text reading of 215 articles was carried out; 200 of those articles were excluded. Fifteen studies lived up to the inclusion criteria.

### Characteristics of included studies

#### Country of included studies

Five of the studies were conducted in Sweden, four in the UK, three in the USA, one in Canada, one in Denmark and one in South Africa (Table 4).

#### Aim of included studies

The included studies aimed at examining experiences and management in relation to family and spouses together ( $n = 3$ ), aspects of everyday life ( $n = 4$ ), experiences in relation to trajectory ( $n = 3$ ), experience of early stages of dementia ( $n = 1$ ), non-specific types of dementia ( $n = 2$ ) and specific types of dementia, including frontotemporal dementia (FTD) and Alzheimer's Disease (AD) ( $n = 2$ ) (Table 4).

#### Methods of included studies

The qualitative approaches used were: individual interviews ( $n = 13$ ), exploratory focus group interviews ( $n = 1$ ) and participant observation ( $n = 1$ ). Four explicitly stated that they used a qualitative design, and one used phenomenological principles. Four used a phenomenological approach, three studies used grounded theory and one used a narrative approach. The sample sizes ranged from two to 34 participants, giving a total of 221 spousal participants. One of the 15 studies did not specify gender (Bergman, Graff, Eriksdotter, Fugl-Meyer, & Schuster, 2016), but of those who did, 118 subjects were females and 93 were males. Six studies reported the duration of the disease, varying from one month to 10 years; two studies reported on dementia in its early stages; one study reported on mild-to-moderate dementia; one reported on mid-stage dementia and five studies did not report the stage of dementia (Table 4).

#### Data analysis of included studies

Nine of the 15 studies specified the analytical strategy; three studies used interpretative phenomenological analysis, one study used phenomenological-hermeneutic analysis, two studies used thematic analysis, two studies used constant comparative analysis, one study used theoretical deductive analysis and six studies did not report the analytical strategy used (Table 4).

### Results from the thematic analysis

Three themes derived from the analysis: 1) Noticing changes in everyday life 2) Transformation to a new marital relation in everyday life 3) Planning the future (Table 6).

#### Theme 1. Noticing changes and management of noticed changes in everyday life

Two of the included studies examined aspects related to time between pre-diagnosis and actual diagnoses, including

Table 4. A review matrix of included studies.

Author, Year, Country, Journal	Purpose	Methods	Analytical strategy and Results
		Approach or Study design, Sample size, Participants and Context	
(1) Hellström et al. (2007)	PwD and their spouses' experiences of dementia over time and their impact on interpersonal relationships and patterns of everyday life.	A grounded theory methodology, consisting of 152 interviews with telephone follow-up (after three, nine and 15 months) over a period of five years Twenty couples, eight male and 12 female spouses, with a mean age of 76 years, who had been living together for between eight and 60 years (median = 49 years). Eight couples had been living together in private houses, and 12 had been living in flats.	A constructivist grounded theory methodology Data showed processes involved in changes over time, how couples managed changes especially in the early stages by maintaining the quality of and closeness in their relationship, and insights into how spouses maximise the quality of the relationship.
(2) Vikström et al. (2008) Sweden Published in: Dementia	PwD and spouses' experiences of mutual engagement in everyday activities	A qualitative interview Twenty-six cohabiting couples, 12 males spouses and 14 females spouses PwD were diagnosed as having mild-to-moderate dementia	A qualitative constant comparative analysis Data showed changes in everyday engagement, and the consequences of the changes, including dilemmas as well as management approaches for handling changed circumstances, loss of social engagements and changes in the relationship.
(3) Quinn et al. (2008) United Kingdom Published in: Aging and Mental Health	Spouses' experiences of their partner during early stages of dementia	Exploratory study using a qualitative methodology: individual semi-structured interviews. Thirty-four spouses or co-habiting partners, six men and 28 females, aged 52-80 years; early-stage dementia.	Analytical strategy, not reported Data showed changes and management in early-stage dementia, including difficulties in understanding the nature and meaning of diagnosis and condition, changes in the relationship, problems and challenges, and ways of coping.
(4) Pretorius et al. (2009) South Africa Published in: Dementia	Males' experiences of caregiving in dementia from a salutogenic perspective.	Qualitative research method, using semi-structured in-depth interviews. Ten white, middleclass male spouses, with a mean age 77	An orientational analysis approach, analysed in terms of Antonovsky's sense of coherence construct. Data showed various stressors that related to changes and how these stressors are managed, using problem-solving strategies rather than emotionally
(5) Fjellström et al. (2010) Sweden Published in: American Journal of Alzheimer's Disease and Other Dementias	Spouses' perception of everyday life aspects of food choices, cooking and food-related work.	Explorative focus group interviews Seventeen spousal caregivers, 11 women and six men	Analytical strategy not reported Data showed how spouses manage the changes brought about by dementia, including struggling with adopting or extending a new role in relation to food-related work.
(6) O'Shaughnessy et al. (2010) United Kingdom Published in: Dementia	Spouses' experiences of how cognitive decline impacts their relationships as a couple and meanings related to these experiences	A phenomenological approach using Interpretative Phenomenological Analysis (IPA), conducting semi-structured interviews with seven spouses, five wives and two husbands, aged 59-86 years, caring for their partners with mid-stage dementia at home.	Interpretative phenomenological analysis (IPA) Data showed changes and management related to changes in the marital relationship
(7) Boylstein and Hayes (2012) United States of America Published in: Health & Social Care in the Community	Spouses' experiences of reconstructing the meaning of closeness in their marriage.	A conceptual framework of narrative reconstruction In-depth interviews Twenty-eight spouses, 13 men, mean age 74, 15 women, mean age 61, caring for their partner who had primarily demonstrated symptoms of Stages II and/or III Alzheimer's disease (AD) for at least six months.	Analytical strategy not reported. Data shows spouses' ability to reestablish a sense of marital closeness, although there were significant changes in social identity. Females were more likely than males to report that perceived changes in spouses' identity altered their own identity within their marriage.
(8) Lin et al. (2012) UK, Scotland Published in: Dementia	Spouses' experiences of caregiving for a partner with dementia over time.	A longitudinal, grounded theory approach, involving in-depth interviews, with follow-up at six and eight months. Six cohabiting married couples, three wives and three husbands, aged 64-72 years, with a caregiving period of between six and 10 years.	A constant, comparative analysis Data showed spouses' experienced life changes in relation to commitment, responsibility and duty, and support.
(9) Boyle (2013) United Kingdom Published in: Journal of Applied Gerontological Society	Married couples' experiences of managing finances and decision making	Qualitative design, ethnographic and creative methods, using participant observation and semi-structured interviews with spousal carer and unstructured interviews with the PwD. 21 married couples, 12 male spouses and 9 female spouses Dementia diagnosis varied from one to 12 years; some were in the early stages and some were in more advanced stages. Two-thirds of the couples occupied 'higher' social class positions: I, II and III	Thematic analysis Data showed that the ways in which couples manage finances are influenced by social factors and that gender had an influence on whether PwD were involved in financial decisions.

(continued)



Table 4. (Continued)

	Author, Year, Country, Journal	Purpose	Methods	Analytical strategy and Results
			Approach or Study design, Sample size, Participants and Context	
			.Non-manual. One-third were in 'lower' class positions: III Manual, IV and V. The sample was predominantly white British couples, but included one south Asian couple.	
(10)	Ducharme et al. (2013) Canada Published in: American Journal of Alzheimer's Disease and Other Dementias	Spouses' experiences of the disease trajectory when living with younger PwD	Qualitative design with principles from phenomenology Individual semi-structured interviews Twelve spousal caregivers, four male spouses and eight female spouses, living with partners with early-onset Alzheimer's disease or a related disorder, diagnosed before the age of 65	Analytical strategy not reported. Data showed various difficulties in managing dementia in early stages, e.g. managing behavioural and psychological symptoms, lengthy quest for diagnosis, nondisclosure to others and denial of diagnosis, grief for loss of spouse, midlife projects, difficulty juggling unexpected role and daily life responsibilities, and difficulty planning for future.
(11)	Madsen and Birkelund (2013) Denmark Published in: Journal of Clinical Nursing	Spouses' and children's experiences of living with a PwD, focusing on similarities and differences between experiences	A phenomenological and hermeneutic approach, inspired by Kristi Malterud's method, systematic text condensation (STC). Interviews, where 21 narratives stories were collected. Three husbands, aged 67-76, seven wives, aged 58-84, eight daughters, aged 45-63 and three sons, aged 38-59.	Systematic text condensation by Kristi Malterud All family members experienced changes, grief and loss. Differences were found between family members. Sons found it easier to adapt to new roles and daughters found it more difficult. Husbands experienced being attacked by the people around them, while wives were found to submit their dementia-suffering husbands to physical abuse. The wives also suffered from self-criticism.
(12)	Massimo et al. (2013) USA Published in: Geriatric Nursing	Spouses' perceived experiences of and responses to living with a person with FTD	Qualitative interviews as data collection method Two wives with a young age and high educational level. Duration of disease: at least two years.	Analytical strategy not reported. Data showed changes in relation to personality, lost adherence to social norms and emotional loss.
(13)	Shim et al. (2013) USA Published in: Applied Nursing Research	Spouses' experiences of finding meaning in caregiving	Descriptive qualitative study Semi-structured interviews 11 spouses, five men and six women, aged 63-81 years. Spouses were self-selected, with at least one year's experience and at least three 3 h a day.	Thematic analysis Data showed that spouses found meaning in their caregiving experiences, and by believing in choosing their attitude and perceiving satisfaction in living according to their values in life.
(14)	Bergman et al. (2016) Sweden Published in: Medicine, Health Care and Philosophy: A European Journal	Spouses' experiences of living with a partner with AD	A phenomenological framework – interpretative phenomenology In-depth interviews Ten spouses to persons with Alzheimer's' disease (PwAD), at least a year after the diagnosis.	An interpretative phenomenology was conducted. Data showed changes in relation to the diagnosis where spouses felt physically and mentally imprisoned due to the changes, and managed their new circumstances by developing new strategies and attitudes to create an extended "lived space" with their partner.
(15)	Hellström et al., (2017) Sweden Published in: Scandinavian Journal of Caring Sciences	Male experiences of approaching the caregiver role over time	A secondary analysis of a subset of male caregivers, who participated in a longitudinal, grounded theory study. Semi-structured interviews were conducted Seven male spouses.	Analytical strategy not reported Data showed how dementia changed the relationship and changed the way male spouses approached and perceived the caregiver role, and how it influenced them as individuals over time.

Table 5. Quality assessment of included studies, Q1 – Q10 illustrates the ten questions included in CASP, Y (Yes) N (No).

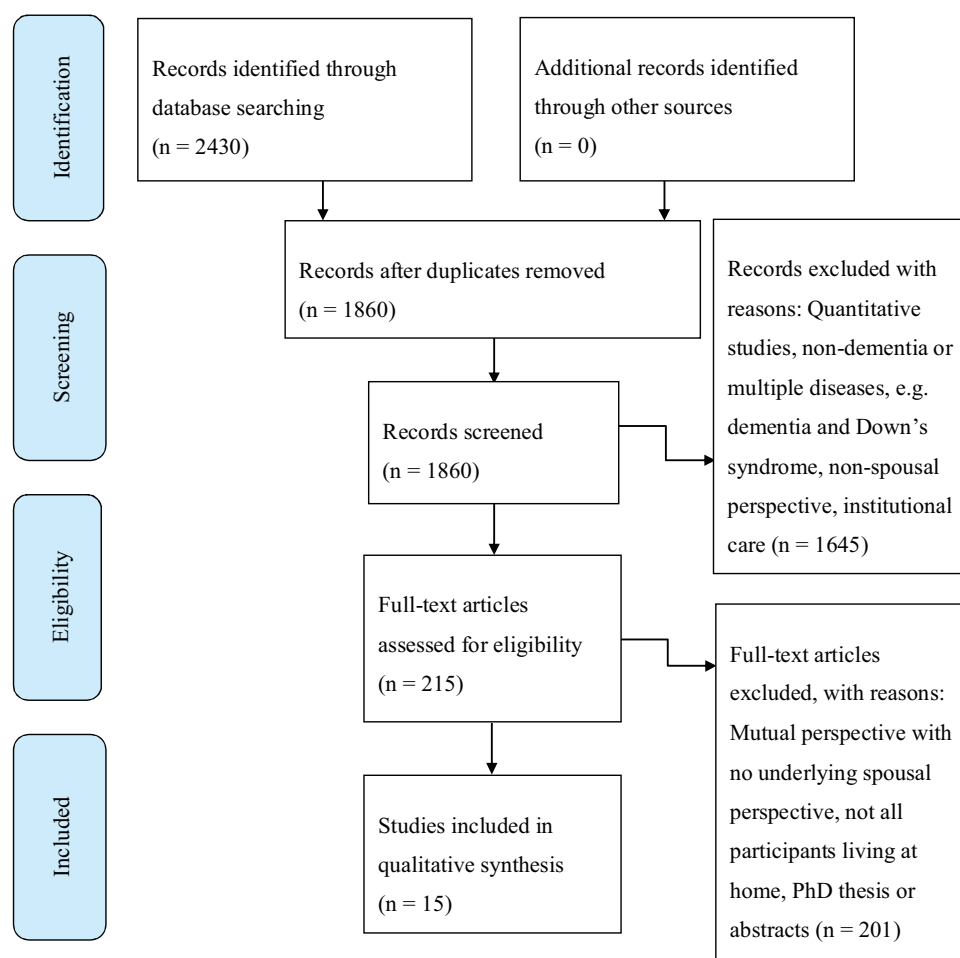
Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Hellström et al. (2007)	Y	Y	Y	N	Y	Y	Y	Y	Y	Y
Vikström et al. (2008)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Quinn et al. (2008)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Pretorius et al. (2009)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Fjellström et al. (2010)	Y	Y	Y	N	Y	N	N	Y	Y	Y
O'Shaughnessy et al. (2010)		Y	Y	Y	Y	N	Y	Y	Y	N
Boylstein and Hayes (2012)	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Lin et al. (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	N
Boyle (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ducharme et al. (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Madsen and Birkelund (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Massimo et al. (2013)	Y	Y	Y	Y	N	N	N	N	N	Y
Shim et al. (2013)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Bergman et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hellström et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Y – Yes, N – No

noticed changes and management of noticed changes in everyday life (Table 6).

Spouses noticed various changes in their partners' everyday lives in relation to pre-diagnosis and diagnosis. Spouses experienced that they had to adjust to their new life situation by trying different strategies to manage their new everyday life, dependent on the extent to which dementia had progressed.

Spouses experienced some changes in their partners' behaviour and personality (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013; Quinn, Clare, Pearce, & van Dijkhuizen, 2008). Nevertheless, spouses sought alternative explanations for their partners' unusual behaviour, such as stress, depression or workload (Ducharme et al., 2013); but when the diagnosis was disclosed, it was experienced as a relief and as an explanation of the irregular behaviour; but it



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

**Figure 1.** PRISMA 2009 Flow Diagram, identification including inclusion and exclusion of studies.

was otherwise linked to uncertainties about future life changes (Ducharme et al., 2013; Quinn et al., 2008). Disclosure of the diagnosis gave rise to a difficult situation, often accompanied by a transitional period of shock. Spouses tended to downplay their partners' problems in the beginning, and denied the fact that their partners had dementia and were unwilling to accept the diagnosis (Quinn et al., 2008).

Spouses tried to manage the disclosure by apprehending their circumstances and trying to understand aspects of the disease (Ducharme et al., 2013). Spouses tried to normalise their circumstances while at the same time acknowledging the need to accept the diagnosis and manage the situation; and they tried to stay independent but realised a needed to stay more at home; they gave up activities and interests and felt isolated from friends and family (Quinn et al., 2008).

Different strategies were used in spouses' ways of communicating, and in their ways of seeking support from their partner in order to cope the condition. Some found it important to communicate about the condition, others found it pointless as their partners kept forgetting what they had just talked about (Quinn et al., 2008). Some spouses were in doubt of their partner's understating of his or her condition, while others spouses felt that their partners were unwilling to talk about the condition (Quinn et al., 2008).

Support from close relations was sought in different ways. Some spouses found it difficult to share the diagnosis with others because of taboo and stigma associated with the disease, leading to the perception that it was a marital concern only (Ducharme et al., 2013). Some spouses sought isolation as they feared not being understood by their closest relations

**Table 6.** Thematic analysis.

Themes	Subthemes	Representative studies
Theme (1) Noticing changes to everyday life		(Ducharme et al., 2013; Quinn et al., 2008).
Theme (2) Transition to new marital relationship	Subtheme (1) Transition in marital relation in everyday life	(Bergman et al., 2016; Boylestein & Hayes, 2012; Ducharme et al., 2013; Fjellström et al., 2010; Hellström et al., 2017; Lin et al., 2012; Madsen & Birkelund, 2013; Massimo et al., 2013; O'Shaughnessy et al., 2010; Quinn et al., 2008; Vikström et al., 2008).
	Subtheme (2) Management of transformed marital relation	(Bergman et al., 2016; Boyle, 2013; Fjellström et al., 2010; Hellström et al., 2017; Hellström et al., 2007; Madsen & Birkelund, 2013; O'Shaughnessy et al., 2010; Pretorius et al., 2009; Quinn, Clare, & Woods, 2009; Shim et al., 2013; Vikström et al., 2008).
Theme (3) Planning the future		(Boylestein & Hayes, 2012; Ducharme et al., 2013; Massimo et al., 2013; O'Shaughnessy et al., 2010; Pretorius et al., 2009).



(Ducharme et al., 2013). Other spouses found it beneficial to talk to friends and joining the Alzheimer's Society, as it helped them understand dementia and proved supportive as mutual experiences were shared (Quinn et al., 2008).

## **Theme 2. Transformation of marital relation in everyday life**

Two subthemes were related to transformation of marital relation in everyday life; (1) changes in marital relationship, (2) management of the transitioned marital relation in everyday life.

**Subtheme 1: changes in marital relationship.** Spouses experienced dramatic changes in their marital relation due to the many changes that appeared. The main issues were changes in marital roles, changes in everyday activities and emotional reactions. These issues appear to be inter-related.

Spouses experienced changes in their marital relationships due to changed roles, and as a consequence of their partners being unable to perform tasks as before (Boylstein & Hayes, 2012; Ducharme et al., 2013; Fjellström et al., 2010; Massimo, Evans, & Benner, 2013; O'Shaughnessy, Lee, & Lintern, 2010; Quinn et al., 2008; Vikström, Josephsson, Stigsdotter-Neely, & Nygard, 2008). Overall, spouses experienced both mental and practical effects as a result of increased responsibility and more duties and worries (Bergman et al., 2016). In addition, male spouses experienced a shift in roles from sharing a mutual relationship to a changed relationship where practicalities were in focus as dementia progressed (Hellström, Håkanson, Eriksson, & Sandberg, 2017).

In everyday activities, spouses took greater responsibility and assumed a greater number of household chores, leading to changed roles (Boyle, 2013; Boylstein & Hayes, 2012; Lin, Macmillan, & Brown, 2012; Quinn et al., 2008; Vikström et al., 2008). Some felt empowered and more dominant due to increased responsibility and decision-making (Boylstein & Hayes, 2012; Quinn et al., 2008). Others found it difficult to assume responsibility and adjust to the new role (Boylstein & Hayes, 2012; Quinn et al., 2008). Some spouses were able to maintain some degree of collaboration and assistance (Vikström et al., 2008). Spouses who previously had worked together on household chores felt lonely, especially when it was difficult to include their partner (Fjellström et al., 2010). The changed role from spouse to caregiver was frustrating for some (Boylstein & Hayes, 2012), especially as the caregiver role became increasingly dominant (Ducharme et al., 2013). Even though spouses spent more time together in their day-to-day lives, the condition negatively affected their mutual engagement in everyday activities (Vikström et al., 2008). Spouses longed to spend time on their own (Bergman et al., 2016; Vikström et al., 2008), and frustrations influenced their mood which, in turn, affected their partners (Vikström et al., 2008).

Emotional reactions occurred due to changes and loss in marital identity, loss in intimacy and the changes within the relationship (Bergman et al., 2016; Boylstein & Hayes, 2012; Madsen & Birkelund, 2013; Massimo et al., 2013). Spouses experienced loss of shared meanings, roles and connection to their spouses (Massimo et al., 2013). This resulted in a progressive diminution of adult interaction where meaningful communication became impossible (Hellström et al., 2017), and lack of meaningful communication led to a loss of intimacy (Boylstein & Hayes, 2012; Massimo et al., 2013; Quinn et al.,

2008). This was a major stressor as spouses longed to have meaningful communication (Pretorius et al., 2009). The loss of meaningful communicating was difficult for spouses who needed intimacy (Bergman et al., 2016). Losing meaningful aspects in everyday life led to isolation and separation (Boylstein & Hayes, 2012; Pretorius et al., 2009; Quinn et al., 2008). Despite having a wordless relationship, some, however, found a kind of intimacy (Bergman et al., 2016).

In addition to losing marital relationships, spouses experienced a dichotomy when trying to meet their own needs and those of their partners, experiencing self-criticism and guilt, at the same time as feeling deep empathy for their partners (O'Shaughnessy et al., 2010). Spouses felt a sense of powerlessness and lack of control over the course of the illness and its consequences for their relationship (O'Shaughnessy et al., 2010). Especially male spouses were affected negatively due to a feeling of detachment from their social network which generally did not understand the illness (Madsen & Birkelund, 2013). Female spouses considered themselves evil when their living circumstances became so challenging that they wished that their partners had died (Madsen & Birkelund, 2013).

**Subtheme 2: management of the transformed marital relation in everyday life.** In the face of the dramatic changes in their marital relationship, spouses actively sought alternatives strategies. The strategies used were: attempts to sustain couplehood, reconstructing marital closeness, developing practical and emotional management strategies and seeking support.

Spouses worked to sustain couplehood and reconstruct marital closeness (Bergman et al., 2016; Boylstein & Hayes, 2012; Hellström, Nolan, & Lundh, 2007; Lin et al., 2012). They tried to sustain their marital relationship by letting their partner continue with social and household chores (Boylstein & Hayes, 2012), thereby distancing their marriage from the illness as a way of reconstructing their marriage (Hellström et al., 2007). Spouses attempted to sustain their marital relationship by adding value and joy to elements of their everyday lives, focusing on former rituals or routines (Hellström et al., 2007). Spouses also tried to prevent and manage potential conflict situations and helped their partner look on the bright side (Hellström et al., 2007). Marital relationships were sustained using humour and by avoiding tense or serious situations, which, in turn, required a tremendous amount of patience (Boylstein & Hayes, 2012). Spouses tried to maintain an open, two-way communication in order to maintain couplehood (Hellström et al., 2007).

Sustaining and reconstructing their marital relationship had an impact on how spouses looked at themselves in their role as spouse or caregiver. Maintaining marital closeness helped them frame their role as a helper where caregiving became part of their marital relationship (Boylstein & Hayes, 2012). If spouses did not successfully reconstruct marital closeness, providing care for their partner became unwanted and was a devastating experience (Boylstein & Hayes, 2012).

Practical and emotional strategies helped spouses create a sense of control over their circumstances, their emotional responses to the changes in their marital relationship and their own sense of self (O'Shaughnessy et al., 2010).

On a practical level, spouses adjusted to their new circumstances by lowering their demands on their partner, themselves and their mutual engagement, and things were kept uncomplicated (Bergman et al., 2016; Quinn et al., 2008; Vikström et al., 2008).

Some balanced between encouraging initiatives from their partner and taking over chores (Quinn et al., 2008; Vikström et al., 2008), while others developed collaborative management, working together or side-by-side on different chores (Vikström et al., 2008). Some partners who previously had habituated chores were still able to manage their situation (Boyle, 2013). Others experienced that it became necessary to take over all of their partners' previous responsibilities and chores (Boyle, 2013; Quinn et al., 2008) and experienced it as challenging (Quinn et al., 2008); some spouses learned new chores by taking housechores classes (Fjellström et al., 2010).

Spouses actively sought support by participating in support groups or research studies (Shim et al., 2013). Male spouses in South Africa could see their potential value, but opted not to join support groups due to a presumption about their predominantly female composition and emotionally expressive climate (Pretorius et al., 2009). On the other hand, male spouses in South Africa viewed their daughters and/or housekeeper as more accessible and dependable sources (Pretorius et al., 2009).

Emotionally, spouses approached their new living circumstances by changing their attitudes (Bergman et al., 2016), choosing a positive attitude and accepting their situation (Shim et al., 2013). Frustrations were managed by trying to understand their partner's behaviour (Massimo et al., 2013). Male spouses approached caregiving in a problem-focused, cognitive way (Pretorius et al., 2009). Spouses tried to provide care to keep their partner as healthy as possible (Fjellström et al., 2010), and some experienced personal growth in putting another human being's needs before their own (Shim et al., 2013). Especially male spouses experienced taking over chores as positive, as it released a feeling of control over the situation (Pretorius et al., 2009), as well as pride as new household chores were learned (Hellström et al., 2017). On the other hand, female spouses felt they were evil when forced to initiate changes such as institutionalising their partner (Madsen & Birkelund, 2013).

**Theme 3: Re-planning and planning the future.** Spouses' emotional management strategies included not thinking about the future, re-planning and planning the future.

Spouses created new meanings and self-understandings, and changed their expectations about the future (Massimo et al., 2013). Even so, they experienced a dichotomy between acceptance and realism about what the future would hold, e.g. uncertainty related to the duration and progression of the disease and how to manage to live with it (Hellström et al., 2017; O'Shaughnessy et al., 2010).

Spouses experienced that to cope emotionally they needed to have a shorter time horizon and to live in the present moment (Hellström et al., 2007, 2017; O'Shaughnessy et al., 2010). These strategies as well as simple denial helped them cope with their overwhelming fear of the future (O'Shaughnessy et al., 2010). Denial consisted in the couples distancing themselves from the disease and trying to live from day to day to reduce anxiety (Hellström et al., 2017). Focusing on the present moment, doing the best they could and staying positive (Hellström et al., 2007; Pretorius et al., 2009; Quinn et al., 2008) helped when the future was experienced as depressing (Hellström et al., 2017). Male spouses focused on immediate changes rather than potential changes (Pretorius et al., 2009), and managed by distancing the illness from their partner (Hellström et al., 2007). However, spouses

acknowledged that it was difficult to make longer-term plans, and described how the future seemed uncertain and unpredictable (Ducharme et al., 2013; Hellström et al., 2017). Being faced with not having a future together as a couple was experienced as a heavy burden (Boylstein & Hayes, 2012).

## Discussion

The aim of this study was to identify and synthesise previous qualitative studies on what characterises spouses' experiences of living with a partner diagnosed with dementia, and how changes in everyday life are managed.

The findings provide an overview of previous qualitative studies on spouses' lived experiences, of the changes and management of these changes in everyday life when living with a person with dementia. The findings show how spouses struggle with practical and emotional challenges in their everyday lives due to their partner's progressive dementia. The findings highlight how changes and new management strategies are used across the entire time span from pre-diagnosis through the mid-stages of progressing dementia to the time of thoughts about the couple's future. The findings further show how in various ways spouses have to adjust to changes in everyday life at various phases in the progression of dementia.

Findings to our those presented in study have been found in previous reviews of spouses' lived experiences, particularly relating to changes in marital relationships and loss (Evans & Lee, 2014; Pozzebon et al., 2016). Evans and Lee's (2014) found that changes are related to loss of companionship and reciprocity. Over time, the husband-and-wife relationship changes to a caregiver-recipient relationship (Evans & Lee, 2014). Similar to our findings, findings from the study by Evans & Lee, 2014 show how changes in the marital relationship are dependent on the partners' roles prior to the onset of dementia. Previous findings show that loss was experienced as a result of changes due to the partner's personality and the lack of communication skills (Evans & Lee, 2014; Pozzebon et al., 2016). In our study, loss in meaningful communication, marital identity and intimacy led to isolation of the spouses.

The identified themes related to spouses' management of changes show how they struggle to manage both practical and emotional changes as they seek to sustain or reconstruct their marital relationships. Wadham et al. (2016) found that a strong connection between couples seemed to have an impact on how they managed the changes related to identity issues, power struggles, fear and distress (Wadham et al., 2016). Our study shows that spouses try to sustain or reconstruct couplehood by preventing potential conflicts and allowing their partner to maintain household chores and by adding joy and value to their everyday life and trying to maintain former rituals and routines. However, due to prevention of loneliness, some turned to friends for support and became involved in the Alzheimer's Society.

The present study contributes to existing literature by showing how spouses experience changes and manage these changes across the entire dementia disease trajectory. The identified changes can be understood in the light of Birte Bech-Jørgensen's concept of unnoticed changes in everyday life. Before receiving the diagnosis of dementia, changes in everyday life seem to be managed by unnoticed adjustments. However, over time, changes are noticed (Bech-Jørgensen,

1994). In the beginning, habits and routines are sustained as far as possible, but when changes in everyday life are unavoidable, people try to create new meaning in their lives and reconstruct everyday life (Bech-Jørgensen, 1994). In our findings, changes in everyday circumstances were related to former roles, routines and habits were influenced by the progression of dementia and the spouses' ability to reconstruct their marital relationship. Reluctantly, spouses had to let go of trying to sustain their former marital relationship and had to seek support elsewhere, creating a new identity and independence. Lay representatives in the panel that we consulted during our study supported the idea of intervention in the early stages, as participants often were not aware of the changes until it was too late. As supported by the panel, interventions in the early stages could have helped them discern unnoticed changes and support them in sustaining and reconstructing the relationship, if needed.

Our review is in line with previous review on spouses' experiences of having to change their marital roles. The findings of the present review highlight the need to keep exploring spouses' and couples' experiences of everyday challenges when living with a person with dementia, particularly in relation to its progression. Future studies need to focus more on developing early interventions that help couples manage and address the sometimes overwhelming changes in their everyday lives and hopefully prevent major crises in marital relationship.

### Strengths and limitations

Our study followed JBI review guidelines, which helped support the identification of relevant literature (Joanna Briggs Institute, 2014). The first author has been in dialogue with a librarian with expertise in search strategies in order to qualify the search. The first author has also been in dialogue with lay representatives discussing findings which, according to JBI, strengthens and helps to qualify the review (Joanna Briggs Institute, 2014), and helped us be reflective about our preunderstanding of what is important to investigate. The use of PICo helped structure the search and helped in identifying relevant qualitative studies by structuring the search in relation to the three key aspects **P**opulation (P), **P**henomena of **I**nterest (I) and **C**ontext (Co).

According to JBI, the timeframe for a literature search can be limited, but may exclude relevant literature (Joanna Briggs Institute, 2014). Studies before 2007 were not included. Using a methodological filter can be a limit as well as strength. Results from quantitative studies could have complemented the qualitative studies. According to Joanna Briggs, including a range of different methodological studies in order to capture the phenomenon of interest is advantageous. Our aim was to identify spouses' lived experiences, which calls for the inclusion of qualitative studies only. When it comes to capturing the different stages in the disease trajectory, not all of the included studies reported the stages of the partner's dementia. This means that the identified themes might not only cover mild-to-moderate dementia, which could affect the conclusion and transferability of the findings. Furthermore, couples of same sex are excluded, and the conclusions presented in this systematic review therefore pertain only to different-gender couples. Articles with low quality were not excluded, which is a limitation. Variation in the various contexts, cultures and countries and spouses' characteristics can

inspire healthcare services to develop spouse and dyad interventions whose aim is to support people in managing everyday life with dementia.

### Conclusion

This review identifies previous studies on spouses' lived experiences of living with a person with dementia. The findings offer a deeper understanding of spouses' experiences of marital changes and management of these changes as they occurs over time, and it contribute with knowledge on spouses' experiences of changes in the early stages of dementia. Furthermore, the present study identifies themes of importance that not only relate to spouses' experiences of changes in marital relationship but also to how these changes are managed in everyday life over time and while the partner is still living at home. The identified themes can help healthcare service providers achieve a better understanding of spouses' lived experiences, and they provide directions for future supportive interventions targeting not only the person with dementia but also the spouse. These interventions could help support spouses manage everyday challenges and if possible ease the burden involved.

### Acknowledgments

We would like to thank Mette Buje Grundsøe, MLISc, Aalborg University Library, for specialised knowledge and support regarding the systematic search for this review.

### Disclosure statement

No potential conflict of interest was reported by the authors.

### Funding

This work was supported by Municipality of Aalborg and University of Aalborg [grant number 2015-035578-22].

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